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**Palliative care: when and how, and what are the implications for global cancer policy?**

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## Highlights

- Palliative care is an essential component of health services. It improves outcomes and saves cost. Despite increasing need for palliative care in all regions of the world, provision is woefully inadequate.
- Despite the needs and benefits for palliative care, investment is poor even in high income countries.
- Integration of palliative care, and quality of death, is greatest in high income countries.
- Some low and middle income countries have shown regional leadership by including palliative care in the National health Plans, and by supporting policy to enhance provision in primary, secondary and tertiary sectors.

### **The concept and practice of palliative care**

Palliative care is defined by the World Health Organization (WHO) as "an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual".<sup>1</sup> The word palliative comes from the Latin *palliare*, meaning *to cloak*. The goal of palliative care is to ease the symptoms and other problems associated with living with an incurable illness, rather than to try to extend the amount of time that the patient has left to live.

In this article the term palliative care will refer to care delivered by health care professionals working in specialist palliative care teams. Specialist palliative care teams are multi-professional, including doctors, nurses, social workers, and other allied health professionals for whom palliative care is their core daily work. Specialist palliative care teams deliver care directly to patients, and indirectly by supporting other professionals to deliver care.<sup>2</sup>

The term hospice is context dependent. In the UK, hospice most often refers to an institution within which the health care professionals are specialists in palliative care. Hospices in the UK usually have inpatient beds, as well as community teams who see patients in their place of residence. In the United States, hospice care is the term used for a Medicare benefit available to people with a prognosis of six months or less.<sup>3</sup> US hospice care is most often provided in the community, with inpatient units being less common.

Since the development of the modern hospice movement by Dame Cicely Saunders in the UK in the 1960's, it has become a global movement (for example the first hospice in Africa opened in Zimbabwe in 1979), and is often recognised as a medical and nursing specialty. Given the advances in the policy, practice and research of palliative care in the UK, in this article we will largely draw on the UK context. However, as an academic collaborative that has focused on palliative care as a global health need, we will also draw on further contexts and lessons learned from around the world. In 2004 the World Health Assembly passed its first resolution on palliative care and so now Governments have a responsibility to train health care professionals in palliative care, deliver appropriate and effective palliative care, and ensure an evidence base.

### **The benefits of palliative care**

There is now a body of evidence from controlled trials that specialist palliative care teams provide improved symptom control, better satisfaction with care, and improved quality of life for patients, and better outcomes for care-givers.<sup>4-7</sup> Systematic reviews have shown that receipt of community-based palliative care is associated with double the odds of dying at home,<sup>8</sup> and half the odds of cancer patients attending Emergency Departments in their last month of life.<sup>9</sup> In the United States, among people with cancer, hospice care was associated with lower rates of hospitalization, intensive care unit admission, and invasive procedures close to the end-of-life.<sup>10</sup> In Canada, community-based specialist palliative care is associated with reduced risk of acute hospital care use, and a higher rate of out-of-hospital death.<sup>11</sup>

Paradoxically, although the aim of palliative care is not to lengthen life, there is early but growing evidence that early palliative care may also improve survival among people with cancer.<sup>12,13</sup> The mechanism of this is unclear but it may be a result of patients receiving less chemotherapy near to the end-of-life, having fewer hospital admissions, or due to improvement in patients' depression.<sup>14</sup> In the UK, trial evidence has shown that a brief palliative care consultant advisory service can reduce symptoms and caregiver burden<sup>15</sup> and costs of care<sup>16</sup>. A further UK trial to integrate palliative care into a novel multiprofessional brief service to manage breathlessness found In addition to self-mastery of breathlessness, it also has a positive survival effect<sup>17</sup>. In an RCT evaluation from Africa, training and use of a basic assessment tool with a care plan in palliative care delivered by existing clinic nurses alongside treatment improved mental health and psychosocial problems<sup>18</sup>.

### **Palliative care reduces the high costs of end-of-life care**

Care costs for people in the last year of life account for a large proportion of total health care expenditure. In the UK, around 20% of hospital bed days are related to the last year of life.<sup>19</sup> In the USA, 25% of total health care expenditure is used in the last year of life.<sup>20</sup>

Annual direct costs for cancer care are projected to rise in the USA from \$104 billion in 2006 to \$173 billion in 2020, driven by dramatic rises in the costs of therapy and the extent of care.<sup>21</sup> These are unsustainable increases. Better integration of

palliative care has been suggested as a potential solution to reducing costs without depriving patients of benefit.<sup>21</sup>

Evidence on the cost effectiveness of palliative care has lagged behind evidence on its effectiveness with respect to patient and family outcomes. This is due to the complexity of capturing social care and informal care costs in addition to health care related costs. Emerging evidence suggests that palliative care is likely to be cost-saving overall. In a systematic review, Smith et al examined 46 studies that reported on costs of palliative care.<sup>22</sup> They found a wide variety of study types, characteristics, and quality. Most of these studies were from the United States, and they included both cancer and non-cancer conditions. Despite these variations, they found a consistent pattern: palliative care was frequently found to be less costly than comparator groups, and in most cases this difference was statistically significant. This indicates that the expense incurred by having an extra team involved in the patient's care is offset by fewer tests and treatments, and less hospital-based care.

### **End-of-life communication**

It has been said that if palliative care was a drug, patients and policy makers alike would demand it. Unfortunately, societal attitudes towards death and dying, and a reluctance to speak about end-of-life care issues, mean that palliative care does not always seem palatable. The 2013 Neuberger review called for a National conversation about death and dying, to dispel some of the taboos that still surround it.<sup>23</sup> Initiatives such as the Dying Matters coalition in the UK, the Death Café movement, and the US Conversation Project encourage the normalization of conversations about dying. However, many people still have a 'not yet' approach to talking about their own mortality.

This is compounded by health care professionals' reluctance to initiate conversations about end-of-life care preferences with their patients. A US study showed that 69% of patients with lung cancer (and 81% with colorectal cancer) were not aware that the intention of their palliative chemotherapy was not to cure their disease.<sup>24</sup> In one study, around half of medical oncologists preferred not to discuss resuscitation, advance directives, or palliative care until there were no more treatment options available.<sup>25</sup> Perhaps not surprisingly, cancer patients who have late end-of-life conversations are more likely to receive overly aggressive care.<sup>26</sup> In the US, recent provision of reimbursement to physicians who have end-of-life conversations with their patients is likely to lead to such conversations becoming more mainstream.

Good end-of-life communication must be initiated by health care professionals, who in turn require adequate education and training. Remarkably, given its ubiquity, it is only relatively recently that caring for people who are dying has become a mainstream part of medical education. While palliative care is slowly gaining prominence on the medical curriculum, still the average time devoted to palliative care is 20 hours over five years.<sup>27</sup>

### **Providing enough palliative care: a lack of investment**

While there is now convincing evidence that palliative care can improve patients' quality of life and death, and frequently at lower costs, investment in palliative care services has been slow and often inadequate. In the UK, palliative care developed from the hospice sector, and historically much of its funding has been private or charitable. Currently, the charitable sector spends £950 million on hospice care annually, with state funding of around £460 million.<sup>28</sup>

There is widespread geographical variation in investment in specialist palliative care services: in 2010/11 the average spend by Primary Care Trusts on specialist palliative care varied from £186 to £6213 per death.<sup>28</sup> Inequalities in palliative care provision are widespread, with evidence of disparity according to diagnosis, age and relative affluence in addition to geographical location.<sup>29</sup>

Improving care for people approaching the end of their lives, and providing care that reflects their individual choices and preferences, has been cited as a priority for the UK Government. The 2015 Choice review calculated that a relatively modest investment - £130 million – could provide a meaningful level of service improvement and greater choice for patients approaching the end-of-life.<sup>30</sup> However, despite the government's commitment to respond to the Choice review by the end of 2015, it is yet to publish its position.

### **Global palliative care provision**

Access to palliative care is recognized as a human right claimable within existing global covenants<sup>31,32</sup>. Palliative care may be even more necessary in low and middle income countries where there is poorer access to health services, later presentation, and fewer curative treatment options.



In 2010, and again in 2015, the Economist Intelligence Unit attempted to rank quality of end-of-life care in 80 countries worldwide according to five indicators: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the level of community engagement. Not surprisingly, rich nations tend to rank highest in terms of quality of end-of-life care. The report showed that countries with a high quality of end-of-life care shared the following qualities:

- A strong and effectively implemented national palliative care policy framework;
- High levels of public spending on healthcare services;
- Extensive palliative care training resources for general and specialised medical workers;
- Generous subsidies to reduce the financial burden of palliative care on patients;
- Wide availability of opioid analgesics;
- Strong public awareness of palliative care.

The WHO global atlas of palliative care has categorized every country according to the level of palliative care integration and provision<sup>33</sup>. While 74 low and middle income countries fall within the worst category (i.e. “no known activity”, e.g. Afghanistan, Bhutan, Senegal, Uzbekistan) it is notable that several African countries fall in the top two categories (“Preliminary integration” and “Advanced integration”, e.g. Kenya, Tanzania, Zambia, Zimbabwe, Uganda and South Africa). Sub-Saharan Africa has achieved much in advancing the policy, training, practice and research of palliative care. African advocacy bodies and services have worked hard to roll out opioid availability in districts<sup>34,35</sup>, to develop and implement simple outcome measures to guide and evaluate care<sup>36</sup>, and to undertake research on physical<sup>37</sup>, social<sup>38</sup> spiritual<sup>39,40</sup> and psychological aspects<sup>41</sup> of palliative care. The WHO foundation measures were designed to assist countries develop a public health approach to cancer palliative care<sup>42</sup>: policy, education, drug availability and implementation. However, these foundation measures must be underpinned by local research that determines *what* the policy should advocate, *how and what* should be taught, *which* drugs need to be available, and *how best* to implement<sup>43</sup>. African has been an exemplar in advancing the science of palliative care, generating the original research urgently needed in the emerging field of global health palliative care<sup>44</sup>. The

African example shows how clinical cultures and public understanding can be changed to endure effective, compassionate and appropriate end-of-life care. Such change is urgently needed in many parts of the world, for example research in Cuba found that advanced cancer patients were often unaware of their diagnosis or prognosis, and that this was associated with greater distress<sup>45</sup>.

Drug availability for the management of advanced cancer pain is a key challenge in many regions<sup>46</sup>. Very economically poor terminal cancer patients and their families in Bangladesh describe spending their few resources on futile treatments, yet not being able to access cheap and effective opioids<sup>47,48</sup>. The patchy coverage of palliative care highlighted in the WHO Global Atlas underlines the challenge of unequal access even within countries. An example of this is India, where the Kerala region has become well known for good availability of community-based palliative care, while other states have very little coverage at all<sup>49</sup>. Similar inequity exists in Africa<sup>50</sup>, and the challenge remains that we must expand global coverage while maintaining quality.

### **Cancer palliative care policy in Africa**

According to the **World Bank Cancer Mortality report of 2012** low- income countries largely in sub-Saharan African contributed a total of 350,000 deaths to cancer mortality of which 70,000 tobacco related cancers and 90,000 deaths were infection related cancers.

Sub-Saharan Africa has a unique cancer picture compared to the rest of the world. It is the only continent where among women cervical cancer is equivalent to breast cancer in prevalence. According to Global Cancer Report 2014 the prevalence of cervical cancer among women in sub-Saharan Africa is 25.2% while breast cancer is 25.5%. Both these are the top cancers for women while prostate and liver cancers are top cancers in men (World Cancer Report 2014).

The dilemma facing most cancer patients are many in Africa is lack of appropriate and accessible services. Most cancer patients in sub Saharan Africa either present late for treatment, or go to facility where appropriate cancer treatment does not exist. There are many cancer patients who never access any form of western medicine services (World Cancer Report 2014).

The situation is changing slowly in terms of cancer policy and cancer control plans in Africa. Zimbabwe and Kenya are model countries that have now adopted model cancer control plans that cover the whole continuum from primary prevention, early detection, diagnosis and treatment, support and rehabilitation as well as palliative care (<http://www.iccp-portal.org/sites/default/files/plans>) and <http://www.iccp-portal.org/cancer-plans>)

Six African countries in namely Swaziland, Mozambique, Malawi, Zimbabwe, Tanzania and Rwanda have national overarching standalone palliative care policies with clear national strategies. Uganda and Botswana have completed national palliative care policy documents which are awaiting approval.

### **Evidence based policy**

As described above, an accumulation of research evidence in recent decades has shown that palliative care is an essential component of cancer services, improves outcomes for patients and their family care givers (who also have high care needs<sup>51</sup>), and reduces health care costs. However, further research is necessary to understand when the 'right' time to introduce palliative care is, and which models of care work best in different settings. Late referral is common, and this means that patients and their families are less able to access low cost, effective care.

In order to answer these questions, investment in research is necessary. Currently in the UK, less than 0.5% of the cancer research budget is allocated to research that aims to improve end-of-life cancer care.<sup>52</sup> In 2010 this money was allocated in 48 separate awards, providing an average of just £25,000 per award. The danger of this piecemeal approach to palliative care funding is to produce a mass of small-scale studies that have little impact, while national policies are developed without an adequate evidence base.

The importance of evidence based policy making in care of the dying is exemplified by the Liverpool Care Pathway.<sup>53</sup> Developed in the late 1990s, the LCP aimed to improve care for people dying outside specialist palliative care settings. Greeted with enthusiasm by policy makers, it was rapidly rolled out nationally, and was endorsed in the National End-of-life Care Strategy. However, following sustained media focus

on its potential harms an independent review in 2013 found that there was a lack of convincing evidence of its benefits, and recommended that the LCP should be phased out.<sup>23</sup>

It is essential that future policies aiming to improve care for people who are dying are based on appropriate evidence, and sustained investment in research is necessary to deliver this.

## **Conclusions**

The nature of illness is changing. As a population, we are living longer and survival from disease is prolonged. This, together with a projected increase in the annual number of deaths,<sup>54</sup> presents an unprecedented challenge for health care systems.

While the search for a cure for cancer occupies many newspaper headlines, the fact that roughly 50% of people diagnosed with cancer will die from it is barely acknowledged. Our societal focus on cure must not come at the expense of openness about what to do when cure is no longer an option. When Aneurin Bevan founded the UK's National Health Service in 1948, his vision was of a cradle to grave health service, freely available to all. However, the huge progress in maternity care in the intervening decades has not been matched by progress in palliative and end-of-life care. Investment in palliative care has the potential to transform the quality of life and death for patients, and lead to improved outcomes in bereavement for their carers, while potentially avoiding burdensome (and expensive) hospital care. As the world's population ages, and costs of care become an important component of health care planning, policy makers must turn their attention to care of the dying. The question is no longer why, but how, effective palliative and end-of-life care is provided.

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